

Step Out for Bleeding Disorders

HFMD MISSION

We dedicate ourselves to advancing the quality of life of individuals and families affected by hemophilia or other bleeding disorders by providing a broad range of services and programs.

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photo by Angie Boyd

Our 4th Annual “Step Out for Bleeding Disorders” Minnesota Walk held on Sunday, August 3, 2014 was a HUGE success, with our Walk Teams raising a total of \$23,899! Add Walk sponsorship and exhibiting to the equation, and the grand total for both walks (St. Paul and Fargo) combined was \$73, 899!

The St. Paul event was held at the Mid-way Parkway Como Park Picnic Pavilion. The mascots, Twinkle (Children’s Hospital and Clinics) and Mudonna (St. Paul Saints) gathered all of our walkers at the start line and KQRS blasted their music to initiate the start and excitement of our Walk! There were a few ambitious participants who ran the whole way, while others enjoyed a lovely stroll around Lake Como.

As everyone finished the walk, they stood in line for the 6 inch sandwiches provided in part by Subway of Mendota Heights. They had a selection of Spicy Italian, Turkey, Ham, BMT, Roast Beef, and Veggie. Byerly’s of Minnetonka generously provided bananas and water to help refuel our walkers. To quench their thirsts, our participants enjoyed a snow-cone where they could decide between blue raspberry or cherry flavors. It was a perfect summer day and those snow-cones hit the spot!

Our entertainment was top notch! Pickles the clown did a fabulous job engaging the children with all of her balloon animals and just clowning around. Two talented volunteers shared their time to express hidden painting skills on the faces of the younger participants! Many walkers enjoyed the photo booth, sponsored by CSL Behring, to capture their painted faces or the balloon animals they received throughout the event.

Around 12:00 PM, our participants and exhibitors gathered around the stage to hear the awards for the top three fundraising teams! To be eligible for the contest, teams had to submit their donated funds by 10:30 AM the day of the Walk. The competition was head-to-head. In third place, was Team Charlie with a total of \$1,750. They received a lawn game, Nickelodeon Universe passes, Mountain Moose passes, and a Mall of America Coupon book! When we say head to head, we really mean it. Our second and first place prizes were only \$54 apart! Our second place winners were Team Naumann with \$4,925! Their prize was a bean bag toss, \$100 worth of play cards at Big Thrill Factory, and \$40 gift card for Punch Pizza. Finally, our first place winners were Team Burke-Romarheim with \$5,104!

continued on page 3

Baxter's vision is a life without bleeds

At Baxter, we will not stop until our vision of a life without bleeds is a reality for all.



Over the years, Baxter has been the leader in providing support and resources for the community.

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To us, continuing to make a meaningful difference one person at a time is our passion and what's behind our unwavering commitment.

Pursuing life without bleeds

Learn more about Baxter resources and support at ThereForYou.com.

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The first place prize was a trip to the National Hemophilia Foundation's Annual Meeting in Washington, DC donated by the Colburn-Keenan Foundation. The Burke-Romarheim family enjoyed this educational trip in September.

Sponsoring the Walk at the \$4,000 Long Strides level was Baxter BioScience, Bayer HealthCare, CSL Behring. At the \$2,000 first steps level we had Biogen Idec, Children's Hospitals and Clinics, CVS Caremark, Mayo Clinic, Novo Nordisk, Pfizer, Sanford Health, University of Minnesota Medical Center- Fairview. Our exhibitors were Accredo, ARJ Infusion, Baxter

BioScience, Bayer HealthCare, Biogen Idec, BioRx, Community Health Charities, CSL Behring, CVS Caremark, Novo Nordisk, Octapharma, Pfizer, and Walgreens. Our Walk wouldn't be the same without our sponsors and exhibitors and we thank you for all your hard work and dedication.

Finally, we would like to give a huge thank you to all of our donors, teams, volunteers and participants. Your energy and passion is what makes this Walk come to life - we wouldn't be able to do it without you!

By Ketrin Vinokur (HFMD Intern)



FIRST PLACE

Team Burke-Romarheim



SECOND PLACE

Team Naumann



THIRD PLACE

Team Charlie

Top 5 Minnesota Walk Teams

Team Burke-Romarheim
\$5,104 raised

Team Naumann
\$4,975 raised

Team Charlie
\$1,750 raised

Team Kennen
\$1,275 raised

Team T
\$755 raised

Top 5 ND Walk Teams

Team Devon
\$3,125 raised

Team Happy Feet
\$1,610 raised

Team Ethan
\$775 raised

Team Solem
\$670 raised

Team Easton 2014
\$575 raised

(Photos on this page by Leslie Parker)



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For information on Bayer's Educational Patient and Community Resources, contact your Hematology Account Executive by calling **1-888-79-BAYER**.



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North Dakota Education Day



Carson Ouellette

The HFMD, in conjunction with Sanford Health's Bleeding Disorders hosted our final partner-events on August 16th and 17th, 2014. Families of North Dakota spent a weekend together filled with education, emotion, support, and empowerment. Saturday was one of the hottest and humid days of the year. Think conditions so sweltering that we had to use windshield wipers to drive, but it wasn't raining! We were lucky to spend it together inside the Holiday Inn Fargo and Convention Center.

Saturday morning started off with a very relaxed social gathering. Muffins and breakfast snacks were served while families and friends came together to learn, network, and play. Members reconnected while visiting with vendors and taking silly, fun pictures together in the photo booth, complete with goofy props.

After the social gathering, parents dropped off their children with Vicki Neis for her forever famous childcare program (Shark Week Theme) and got down to business. North Dakota breaking off from the HFMD became a reality when organizers and presenters, Courtenay Misheski and Jana Suder informed the group that ND will be forming their own chapter effective January 1st, 2015, to better meet the needs of ND families. The HFMD would like to thank North Dakota for their love and support over the past years. We will always be your neighbor and forever be a friend and resource.

Saturday's keynote speaker, Carson Ouellette, shared his life story and inspired the group. If ever there were a person to take a challenge and turn it into a success, it is Carson! Carson wanted everyone to take away from his presentation that with a bleeding disorder or caring for one, you have to take what you have and make the best of it. The number of groups, camps, scholarships, internship programs that Carson participated in was astonishing. Carson wants everyone to know the support is there, you just have to reach out and take advantage of it!

It was then time for fun and more time with the kids. After families rejoined with their little ones, the Holiday Inn chef gave a private demonstration of nutritious afternoon snacks. A few kiddos volunteered their efforts and food tv-drama skills while assisting Chef Allan in the preparation of peanut butter banana spirals, strawberry-peach smoothies, and popcorn balls. Upon completion of Chef Allan's HFMD Healthy Snack Show, we were all thrilled to be allowed to try each mouth watering treat!

After snack time, the children returned to "Shark Week" and the rest ended the afternoon with a supportive family-like panel of Whitney Roske (mom of a 2-year-old with hemophilia), Adam Bohrer (young adult with hemophilia), Sherri Ouellette (mom of a young adult and grandchild with hemophilia), and Bob Stone (adult with hemophilia). We were left with a strong impression that members from North Dakota have always been there for each other...and always will. The panel was followed by a physical therapy and fitness activity by Linda Thorseth, PT, Sanford.

The full day was concluded with games and rides at Thunder Road, "where the action never stops"...well, unless it rains. Before the wind and rain made an appearance, we were able to take advantage of Thunder Road's go-karts, 18-hole mini-golf, bumper cars, softball batting cages, and our weather-safe haven-their video arcade. The rain settled and the sun set, leaving us with the hopes that the rain wouldn't come again the next day for our North Dakota 2nd Annual Walk Fundraiser, "Step Out for Bleeding Disorders".

By Carrie Kissoon, HFMD Event Coordinator

Step Out for Bleeding Disorders - North Dakota



Ketrin Vinokur, Carrie Kissoon, Jake Byers

HFMD supporters woke up on Sunday to a city covered in nothing but rain clouds. As setup volunteers and staff approached the beautiful Lindenwood Park it was as if Mother Nature heard our calls. Just as we drove in to a sopping wetland, temperatures became walk-perfect and the rain subsided. We filled the park with a superabundance of red balloons, red and white balloon pillars, and neon orange Walk T-shirts. It was an enchanting sight and turned out to be a beautiful day for a Walk!

At 10 o'clock, family and friends united, ready to celebrate all of their hard work and dedication. Walkers spent the morning socializing, running around with Thundar, NDSU's bison mascot, eating freshly popped popcorn, wearing crazy twisted balloon art, all while BOB95 filled the park with sounds of new country music. The BOB radio mascot made a cameo appearance at the finish line, cheering on and congratulating our walkers before everyone darted for lunch.

Our 2nd Annual "Step Out for Bleeding Disorders" North Dakota Walk was a HUGE success, in ALL respects. With a \$5,000 goal, our Walk Teams raised over \$7,000! A special shout out to our prize winners – our top 3 teams! In 1st place: Team Devon raised \$3,125, 2nd place: Team Happy Feet raised \$1,610, and in 3rd place Team Ethan raised \$775! We would also like to thank the following sponsors of both HFMD Walks: Baxter BioScience, Bayer HealthCare, CSL Behring, Biogen Idec, Children's Hospitals and Clinics, CVS Caremark, Mayo Clinic, Novo Nordisk, Pfizer, Sanford Health, and the University of Minnesota Medical Center- Fairview.



Sincerest thanks to everyone who fundraised, volunteered, donated, and participated in our 2nd Annual North Dakota Walk. The HFMD family in North Dakota is strong, mindful, and so unbelievably caring and supportive of one another. We hold an endless amount of gratitude for all that you have done to make the North Dakota 2013 & 2014 Walks so successful. We wish you luck and even greater success in future Walks.

By Carrie Kissoon, HFMD Event Coordinator



BeneFix®
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- Established safety record
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IMPORTANT SAFETY INFORMATION FOR BENEFIX

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash or hives.
- Your body can make antibodies, called “inhibitors,” which may interfere with the effectiveness of BeneFix.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

- Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

WHAT IS BENEFIX?

BeneFix® Coagulation Factor IX (Recombinant) is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

Please see brief summary of full Prescribing Information on next page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

*BeneFix was approved February 11, 1997.

†IMS National Prescription data October 2013.



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Rx only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-934-5556.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing
difficulty breathing
chest tightness
turning blue (look at lips and gums)
fast heartbeat
swelling of the face
faintness
rash
hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE BeneFix. BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Store the diluent syringe at 36° to 86°F (2° to 30°C). Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

Different storage conditions are described below.

Product labeled for Room Temperature Storage**Store at 2° to 30°C (36° to 86°F).**

If you have the product kit labeled for room temperature storage, it can be stored at room temperature (below 30°C or 86°F) or in the refrigerator (2° to 8°C or 36° to 46°F).

Product labeled for Refrigerator Storage**Continuous refrigeration**

[2° to 8°C (36° to 46°F)]

If you have the product labeled for storage in the refrigerator (2° to 8°C or 36° to 46°F) and you have not taken the kit out of the refrigerator, then the expiration date printed on the package still applies. You can store the product at room temperature (below 30°C or 86°F) for up to 6 months or until it has reached its expiration date, whichever comes first.

If you have taken the product kit labeled for storage in the refrigerator out of the refrigerator and stored it at room temperature (below 30°C or 86°F), then use the product within 6 months from the time you took the product out of the refrigerator or until it has reached its expiration date, whichever comes first. If you cannot remember when you took it out of the refrigerator, then subtract one year (12 months) from the date that is printed on the end flap of the carton package. The date you get is your new expiration date. Throw away any product that has gone over the new expiration date.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use BeneFix for a condition for which it was not prescribed. Do not share BeneFix with other people, even if they have the same symptoms that you have.

If you would like more information, talk to your doctor. You can ask your doctor for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® Coagulation Factor IX (Recombinant) Prescribing Information LAB 0464 8.0, revised November 2011.

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Phyllis Bunker
Betty Cassidy
Tim & Kelly Cassidy
David Christenson
Lois Clark
on behalf of Easton Olson
Amanda Copeland
Robert Crep
Melissa Cummins
Thomas Curley
Susan Curoe
Kelsey Dalby
Jean M. Daniels
Chip Davis
Ellen Depp
Adrienne Donze
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Thumbs Up, Blood Brothers!

The HFMD has been a part of the Hemophilia Federation of America's Blood Brotherhood program since 2010. Through the Blood Brotherhood program the HFMD organizes a number of events for adult men living with hemophilia. The events range from peer-led rap sessions to Timberwolves games and commonhouse outings. Each event is designed to offer a night out to reconnect with one another and help keep men connected and involved with the HFMD and our community.

September 25th, 2014 was a beautiful fall evening in Downtown Minneapolis, sunny and 80 degrees. The Blood Brothers gathered at ACME Comedy Co. in the Warehouse District's Historic Itasca Building for a night of education, food, and laughs - lots and lots of laughs!

To start the night off, the U of MN Center for Bleeding and Clotting Disorder's own Kim Baumann, MPT lead the guys through an informal, interactive conversation about starting a new activity and/or exercise program. After reaching out to the guys for specific topic ideas a few weeks prior, Kim centered her presentation on a member's recent run-in with tennis elbow, ways to prevent it, and general ways to guardedly try new things and prevent injury. Kim concluded the talk with what to do if an injury does occur. Kim brought a number of handouts for everyone, including one on the ever important RICE acronym: Rest, Ice, Compression, and Elevation. This topic and handout brought

about some great discussion where the guys shared stories about past injuries and how they cared for them. After having the entire comedy club exclusively to ourselves, we moved into the comedy club's restaurant, Sticks, for a delicious dinner – chicken, steak, and ribs were top choices among our group.

During dinner, we learned that a couple guys were reunited that night for the first time in 10 years! They had met in the hospital when they were very young, during one of their first bleeds. Their families kept in touch after that emergency visit. The guys eventually became the best of friends and ended up spending many years together on a regular basis and at camp. As we all listened to their stories, others would join in and realized they also spent time together as kids. Many childhood stories and jokes were shared. Everyone felt very honored to be a part of their reunion.

As you can imagine, being at ACME, the remainder of the evening was spent laughing together at some really great comics. It was a perfect way to conclude our night. There's just something about live comedy that brings people closer together.

If you or an adult male that you know is affected by hemophilia and would like to join the Blood Brotherhood, please contact Carrie Kissoon at: carriek@hfmd.org.



A Big Decision

It was a tough decision—stay home and play baseball with my team, or attend hemophilia camp. With no regret, I chose camp. When I got to camp the scenery was great. It was beautiful. The kids were great too. I was friends with everyone in my cabin.



The counselors were nice. I liked each one there. At first I was sad because, while all the kids can get in every year,

all the counselors can't. Some from last year were not able to be there this year. They don't always get to go twice in a row.

I would like to thank some of this year's group. They are: Tony, Patrick, Ryan, Ben, Verune and Brad. They were my favorite counselors.

I got some practice infusing myself. The counselors motivated me and it helped. Patrick even tried it and it worked the first time. He got right in!

I did not miss my electronics at all, which surprised me. I never even thought about it. We were busy playing chess or some other board game. We also played dodgeball, kickball, soccer and relay races. It was really fun. We went to the waterfront and saw a porcupine. We took some pictures. It was really funny. And we went tubing, which was great—one of the best things I've ever done.

Those are just some of the reasons to go to camp. It is also why there is no doubt I will be back next year!

By Daniel (HFMD camper age 10)



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NHF Annual Meeting 2014

The National Hemophilia Foundation held their Annual Meeting in Washington, D.C., September 18-20, at the Marriott Wardman Park. With over 2500 attendees from coast to coast, some stayed at overflow hotels nearby including the Omni Shoreham, a classic hotel built in the 1930s.

Minnesota and the Dakotas were well represented at the conference by Board President John Schulte, Vice President, Mike Neubert attending his first NHF conference, and Executive Director Jim Paist. In addition two families from the HFMD attended, one which HFMD helped to get there, and another family who won our donated Keenan Colburn Foundation travel grant at our Walk in St. Paul on August 3rd. There were also numerous attendees from HFMD affiliated Hemophilia Treatment Centers (HTCs).

Attendees of the NHF Annual Meeting include “consumers” patients and families affected by bleeding disorders, HTC & chapter board/staff, industry sponsors and exhibitors. The primary focus of the conference is education sessions with detailed tracts for each segment of attendees. The HTC tract is delineated into categories for medical, physical therapy, and social worker attendees.

Education session began Wednesday, September 17th, while the conference officially opened Thursday evening with a presentation from NHF’s CEO, Val Bias. Val reflected on the amazing success the bleeding disorders community has had in passing the Ricky Ray Act in the 1990s, and more recently playing a crucial role in eliminating lifetime caps on health insurance included in the Affordable Health Care Act of 2010.

The chapter tract sessions featured presenters on fundraising, board development, and a fascinating presentation from Steven Pipe, MD (hematology) who outlined exciting progress being made in new blood-clotting factor therapies. As a chapter tract attendee, it is always interesting to learn what other chapters around the country are doing for member programs and services.

One of the highlights of the conference is the exhibit hall where pharmaceutical and home care companies share important information about the latest products and services. Some of the companies also have games and contests at their booths which creates a fun carnival atmosphere inside the exhibit hall. NHF staff worked their tails off in putting together a conference of this scale and they did a terrific job in making the event a success!

By Jim Paist

HFMD is a member organization of



Novo Nordisk and Jeffrey Leiken Kick Off HeroPath™ for Teens and Young Adults With Hemophilia

Novo Nordisk announced the launch of HeroPath™, an empowering, yearlong program that connects teens and young adults with life coach and peer support to help them excel in their daily lives and chart a clear path forward. Working in partnership with creator Jeffrey Leiken, the company recently kicked off the program in Chicago with Leiken's team of expert coaches and young people with hemophilia A or B with or without inhibitors.

HeroPath™ is designed to help teens and young adults during this critical transitional stage in their lives through the development of a personal core success strategy. Throughout the kickoff weekend, participants and coaches took part in dynamic group sessions, as well as in one-on-one discussions about personal and professional success, including developing positive relationships and decision-making skills, identifying strengths, gaining confidence, and making thoughtful career decisions.

The weekend laid the groundwork for the yearlong personal coaching program designed to offer tools to participants to be more successful professionally and personally.

The program was inspired by data uncovered through Novo Nordisk's Hemophilia Experiences, Results, and Opportunities (HERO) initiative—the largest international study on the psychosocial impact of hemophilia on patients and their loved ones—supporting the need for additional education on how to manage life transitions and interpersonal relationships.^{1,2} People living with hemophilia reported not only that hemophilia creates additional burden and stress in their daily lives, but also that they are worried about the impact the disorder may have on their future years.^{1,2}

Staff News

HFMD is pleased to welcome Kerry Budinger on staff as our new Administrative Assistant. Kerry brings a high level of skill and experience to the position. She began her tenure with this organization on August 7th and is off to a great start in the office.

We would like to extend a special thank you to Ketrin Vinokur who did a terrific job as our summer intern. Ketrin worked closely with HFMD Event Coordinator Carrie Kissoon in organizing both of our Walk fundraisers and Dakotas Education Event.

Venline

NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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2014-2015 Calendar of Events

November 1, 2014.....Group Fitness Event
Laser Tag & Bowling at Pinz in Oakdale
11 a.m. Call HFMD to R.S.V.P.

February 21, 2015.....Hearts of Hope Gala
Radisson Blu, Bloomington

April 10-11, 2015.....HFMD Annual Meeting
Crowne Plaza, Bloomington

****The HFMD Board of Directors meets quarterly on the fourth Tuesday at 7:00 p.m.****

Visit our web site, www.hfmd.org, for exciting news and updates!